

# Hospice and Palliative Care

## Quality of Life at the End of Life



For many seriously ill patients, hospice and palliative care offers a more dignified and comfortable alternative to spending your final months in the impersonal environment of a hospital. Palliative medicine helps you manage pain while hospice provides special care to improve the quality of life for both you as the patient and your family. Seeking hospice and palliative care isn't about giving up hope or hastening death, but rather a way to get the most appropriate and best quality care in the last phase of your life.

## What is hospice and palliative care?

Although death is a natural part of life, the thought of dying understandably still frightens many of us. You may imagine pain and loneliness, spending your final days in the cold, sterile environment of a hospital far from family, friends, pets, and all that you know and love. However, hospice care represents a compassionate approach to end-of-life care, enhancing the quality of your remaining life and enabling you to live as fully and as comfortably as possible.

Hospice is traditionally an option for people whose life expectancy is six months or less, and involves palliative care (pain and symptom relief) rather than ongoing curative measures, enabling you to live your last days to the fullest, with purpose, dignity, grace, and support. While some hospitals, nursing homes, and other health care facilities provide hospice care onsite, in most cases hospice is provided in the patient's own home. This enables you to spend your final days in a familiar, comfortable environment, surrounded by your loved ones and supported by hospice staff.

The term "palliative care" refers to any care that alleviates symptoms, and can be helpful at any stage of an illness, even when there is still hope of a cure by other means. It is an approach that focuses on the relief of pain, symptoms, and emotional stress brought on by

serious illness. In some cases, palliative treatments may be used to alleviate the side effects of curative treatment, such as relieving the nausea associated with chemotherapy, which may help you tolerate more aggressive or longer-term treatment.

## Talking about hospice and palliative care

For many of us in Western society, death remains a taboo subject. Consequently, many patients and their families remain reluctant to even discuss the possibility of hospice care or palliative care. While most people would prefer to die in their own homes, the norm is still for terminally ill patients to die in hospital, receiving treatment that is either unwanted or ineffective. Their loved ones usually have only limited access and often miss sharing their last moments of life.

Some families who do choose hospice care often do so only for the last few days of life, and later regret not having more time to say goodbye to their loved one. To ensure that your family understands your wishes, it's important for anyone with a life-limiting illness to learn all they can about hospice and palliative care and discuss their feelings with loved ones before a medical crisis strikes. When your loved ones are clear about your preferences for treatment, they're free to devote their energy to care, compassion, and making the most of the time remaining.

## Planning for the future

If you became unable to direct your own medical care because of illness, legal documents such as a Living Will, Power of Attorney, or Advanced Directive can set forth your wishes for future health care so your family members are all clear on your preferences.

Laws differ between countries and states, so consult a lawyer or read [Advance Health Care Directives and Living Wills](#).

## How hospice and palliative care works

As a patient, hospice care focuses on all aspects of your life and well-being: physical, social, emotional, and spiritual. There is no age restriction; anyone in the late stages of life is eligible for hospice services. While specific hospice services around the world differ in the amenities they provide, most include a hospice team that may include your physician, a hospice doctor, case manager, registered nurses and licensed practical nurses, a counselor, dietician, therapist, pharmacologist, social workers, a minister, and various trained volunteers.

The hospice team develops a care plan tailored to your individual need for pain management

and symptom relief, and provides all the necessary palliative drugs and therapies, medical supplies, and equipment. Typically, hospice care is provided in the comfort of your own home and a family member acts as the primary caregiver, supervised by professional medical staff. Hospice providers make regular visits to assess your needs and provide additional care and services, such as speech and physical therapy, therapeutic massage, or dietary assistance. Certified home health aides may also be deployed for help with bathing and other personal care services.

As well as having staff on-call 24 hours a day, seven days a week, a hospice team provides emotional and spiritual support according to your needs, wishes, and beliefs. And emotional and spiritual support is also provided to your loved ones, including [grief counseling](#).

## The benefits of hospice and palliative care

Just as obstetricians and midwives lend support and expertise at the start of life, hospice care providers offer specialized knowledge and support at the end of life. When you're terminally ill, hospice can reduce anxiety for both you and your family by helping you make the most of the time remaining and achieve some level of acceptance. In fact, research published in the *Journal of Pain and Symptom Management* found that terminally-ill patients who received hospice care lived on average 29 days longer than those who did not opt for hospice near the end of life.

- As a terminally ill patient, often already in a weakened physical and mental state, making the decision to receive hospice care instead of continued curative treatment can help avoid the dangers of over-treatment.
- In-home care from a hospice team often means you receive greater monitoring than you would in a hospital.
- In addition to focusing on your physical health and comfort, hospice care also focuses on the emotional needs and spiritual well-being of both you and your loved ones.

### Misconceptions about Hospice and Palliative Care

Misconception	Reality
Hospice makes death come sooner.	Hospice neither hastens nor postpones dying. The aim is to improve the quality of your remaining life so you can enjoy time with family and friends and experience a natural, pain-free death. In some cases, hospice care can extend life.
Hospice is giving up hope; it's better to fight for life.	Most terminally ill patients experience less anxiety by refocusing hope on what might be realistically achieved in the time remaining. If continuing uncomfortable and painful curative treatment for an illness is fruitless, you may benefit more from having your symptoms treated instead.

## Misconceptions about Hospice and Palliative Care

A hospice patient who shows signs of recovery can't return to regular medical treatment. If your condition improves, you can be discharged from hospice and return to curative treatment, or resume your daily life. If need be, you can later return to hospice care.

A hospice patient can't change their mind and return to curative treatment even if their prognosis hasn't changed. A patient can go on and off hospice care as needed—or if you change your mind and decide to return to curative treatment. You may also enter hospital for certain types of treatment that involve improving your quality of life.

Hospice care is limited to a maximum of six months. In the U.S., many insurance companies, as well as Medicare, require that you have a prognosis of six months or less to start hospice, but you can receive hospice care for as long as necessary.

## A guide to hospice care services

Hospice care services are typically structured according to the needs and wishes of you, the patient, and your family. These may change over time and during the three different stages of care:

- The last phases of an illness
- The dying process
- The bereavement period

Depending on your circumstances and stage of care, a hospice team may provide any combination of the following services:

**Nursing Care.** Registered nurses monitor your symptoms and medication, and help educate both you and your family about what's happening. The nurse is also the link between you, your family, and the physician.

**Social Services.** A social worker counsels and advises you and your family, and acts as your community advocate, making sure you have access to the resources you need.

**Physician Services.** Your doctor approves the plan of care and works with the hospice team. In a full hospice program, a hospice medical director is available to the attending physician, patient, and hospice care team as a consultant and resource.

**Spiritual Support and Counseling.** Clergy and other spiritual counselors are available to visit you and provide spiritual support at home. Spiritual care is a personal process, and may include helping you explore what death means to you, resolving "unfinished business," saying goodbye to loved ones, and performing a specific religious ceremony or ritual.

**Home Health Aides and Homemaker Services.** Home health aides provide personal care such as bathing, shaving, and nail care. Homemakers may be available for light housekeeping and meal preparation.

**Trained Volunteer Support.** Caring volunteers have long been the backbone of hospice. They're available to listen, offer you and your family compassionate support, and assist with everyday tasks such as shopping, babysitting, and carpooling.

**Physical, Occupational, and Speech Therapies.** These hospice specialists can help you develop new ways to perform tasks that may have become difficult due to illness, such as walking, dressing, or feeding yourself.

**Respite Care.** [Respite care](#) gives your family a break from the intensity of caregiving. A brief inpatient stay in a hospice facility, for example, can provide a "breather" for both you and your family caregivers.

**Inpatient Care.** Even if you are being cared for at home, there may be times when you'll need to be admitted to a hospital, extended-care facility, or a hospice inpatient facility. Sometimes medical intervention may be recommended to ease the dying process, requiring round-the-clock nursing care at a facility. Your hospice team will arrange for any such inpatient care, and remain involved in your treatment and with your family.

**Bereavement Support.** Bereavement is the time of mourning we all experience following the loss of a loved one. The hospice care team will work with your surviving family members to help them through the grieving process. Support may include a counselor or trained volunteer visiting your family at specific periods during the first year, as well as phone calls, letters, and support group recommendations. The hospice team will also refer your loved ones to medical or other professional care if necessary.

## When is it time for hospice and palliative care?

If you are currently benefiting from treatments intended to cure your illness, then there's no reason to consider hospice care. And while palliative care can be useful at any stage of an illness, including in alliance with curative treatment, for some terminally ill patients, there comes a point when curative treatment is no longer working. Continued attempts at treatment may even be harmful, or in some cases treatment might provide another few weeks or months of life, but will make you feel too ill to enjoy that time. While hope for a full recovery may be gone, there is still hope for as much quality time as possible to spend with your loved ones, as well as hope for a dignified, pain-free death.

There isn't a single specific point in an illness when you should ask about hospice care; it very much depends on you as an individual. The following are signs that you may want to

explore options with hospice care:

- You've made multiple trips to the emergency room, your condition has been stabilized, but your illness continues to progress significantly, affecting your quality of life.
- You've been admitted to the hospital several times within the last year with the same or worsening symptoms.
- You wish to remain at home, rather than spend more time in the hospital.
- You have decided to stop receiving curative treatment for your disease.

## Who is eligible for hospice care?

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To be eligible for hospice care under Medicare in the U.S., your doctor needs to have certified your prognosis as six months or less. This applies to anyone of any age, with any type of illness. Of course, the specific requirements may vary in other countries.

## How to choose a hospice care service

Many of us can be reluctant to question doctors or other medical professionals about the specific services and quality of care they provide. Yet asking lots of questions now can ensure that you or your loved one receive the most appropriate care during this final phase of life.

When choosing a hospice team, be sure to ask about:

- The hospice's patient-to-caregiver ratios for each hospice discipline.
- Average frequency of home hospice visits.
- Response time and procedures for after-hours questions and concerns.
- Continuity of care (i.e., having the same care providers over time).

Also, ask whether the hospice will develop a written treatment plan that is given to all service providers for smooth coordination of care. You and your family members should receive copies of the care plan as well, listing specific duties, work days and hours, and the contact information for the hospice care supervisor.

## Questions to ask a hospice care service

Some other questions to ask when considering a hospice care program:

- Is the program accredited by a nationally recognized accrediting body, such as the Joint Commission on Accreditation of Healthcare Organizations or Medicare in the U.S.? This means that the organization has voluntarily sought accreditation and is committed to providing quality care.

# HelpGuide

- If applicable, is the program licensed (by your state, for example)? Are caregivers licensed and bonded?
- Can the program provide references from professionals, such as a hospital or community social workers? Talk with these people about their experiences.
- How flexible is this hospice in applying its policies to each patient or negotiating over differences? If the hospice imposes conditions that feel uncomfortable to you, that may be a sign that it's not a good fit.
- Is a care plan carefully developed for each patient and their family? Does a nurse, social worker, or therapist conduct a preliminary evaluation of the types of services needed in the patient's home?
- How much responsibility is expected of the family caregiver? What help can the hospice offer with filling in around job schedules, travel plans, or other responsibilities?
- What are the program's policies regarding inpatient care? Where is such care provided?
- Is there a 24-hour telephone number you can call with questions? Try it to see how the hospice responds to your first call.

Source: *Hospice Net*

## Where to turn for help

### Finding hospice and palliative care in the U.S.:

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[National Agency Location Service](#) - Search for home care and hospice by location, payment types, services offered, and more. (National Association for Home Care and Hospice)

[Find a Hospice](#) - Searchable directory for finding a hospice. (NHPCO)

### Finding hospice and palliative care in other countries:

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[Find a hospice](#) - Searchable database of hospice and palliative care services in the UK and Ireland. (Hospice UK)

[Directory of Services](#) - Searchable database of hospice and palliative care services in Canada. (Canadian Hospice Palliative Care Association)

[Directory of Services](#) - Find palliative care providers in Australia. (Palliative Care Australia)

## Recommended reading

[Learn About End-of-Life Care](#) - Includes information on choosing a hospice. (NHPCO)

[What Is Hospice Care?](#) - Hospice and palliative care targeted to cancer patients. (American Cancer Society)

[Hospice Care](#) - Curated collection of links to information and research on hospice care. (MedlinePlus)

[How to Choose](#) - Includes questions to ask when meeting with potential end-of-life care program representatives. (Hospice Foundation of America)

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